

NPM #12: Percentage of newborns who have been screened for hearing before hospital discharge.

Impact on National Outcome Measures: The WSB Program was created to promote EHDI statewide and to meet the goals as outlined in Healthy People 2010; the 2000 Statement of the Joint Committee on Infant Hearing; the American Academy of Pediatrics Policy Statement on Newborn Hearing Screening; and Wisconsin Statute 253.115.

a) Report of 2003 Major Activities

1. Outreach and Public Education—Enabling Services—Pregnant women, mothers, and infants

WSB provided a quarterly newsletter to over 3,000 EHDI stakeholders. The publication "Babies and Hearing Loss: A Guide for Providers about Follow-up Medical Care" went through a second printing due to high demand. WSB documents are available at www.infanthearing.org.

2. Home Births Initiative—Direct Health Care Services—Pregnant women, mothers, and infants

The home birth outreach program has provided families in two regions access to hearing screening and appropriate educational materials. Midwives are now reporting hearing screening information on the NBS blood card. Analysis of blood card data shows approximately 31% of home births were screened in 2003.

3. WSB/Congenital Disorders Program—Population-Based Services—Pregnant women, mothers, and infants

WSB helped write the July 2003 NBS program newsletter, devoted to completion of hearing screening data. WSB helped NBS develop a directory of hospital follow-up contacts. WSB recommended revisions to hearing screening data fields, based on user feedback and data analysis. Blood card data from January 1, 2003 - December 31, 2003 indicated 64,082 (92%) of babies were screened; 995 (1.4%) referred; 3,437 (4.9%) incomplete data; 993 (1.4%) NICU; 95 (0.1%) refused.

4. Birth to 3 Technical Assistance Network—Infrastructure Building Services—CSHCN

Sixteen people were trained to become Early Intervention (EI) consultants, who hosted regional trainings, and provided direct EI services to children who are deaf or hard of hearing. Consultants recruited parents for family programs and events, such as the annual parent conference. The consultant trainers conceptualized the new Guide-By-Your-Side program in 2003.

5. Support Services for Parents—Enabling Services—CSHCN

Families from around the state came together for a two-day Parent Summit in January 2003. Three recommendations from this group were implemented during 2003. 1) June 2003: over 30 families attended the First Annual Conference for Families of Children who are Deaf or Hard of Hearing 2) Parents discussed starting a parent-led organization, after hearing conference keynote speakers, and 3) Statewide listserve/website where a calendar of events and list of resources can be maintained was established.

6. WE-TRAC—Infrastructure Building Services—CSHCN

Eleven hospitals started using WE-TRAC in January 2003. Based on user feedback, a new NICU workflow was added to WE-TRAC, and WSB began defining report specifications. In addition to five audiology clinics, one birthing unit, and four NICUs joined the pilot, now representing almost 25% of births. Users made referrals and entered screening and diagnostic results.

b) Current 2004 Activities

1. Support Services for Parents—Enabling Services—CSHCN

The Second Annual Conference for Families of a Deaf or Hard of Hearing Child was planned by parents and sponsored by the Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESPDHH) Outreach Program with support from DPI, DHFS and WSB. Attendance was double that of the first conference.

The Guide-By-Your-Side (GBYS) program, a parent support program, grew out of the 2003 Parent Summit. GBYS is funded by a DPI discretionary grant administered by the WESPDHH-Outreach program. GBYS matches trained parents ("Parent Guides") with parents of newly identified children who are deaf or hard of hearing. Parent Guides are paid for up to three visits to provide support, unbiased information and connections to resources like early intervention. Bilingual Parent Guides fluent in Spanish and ASL are available statewide.

2. Wisconsin Sound Beginnings (WSB)/Congenital Disorders Program—Population-Based Services—Pregnant women, mothers, and infants

The NBS program distributed a revised blood card with changes to hearing screening fields. WSB contributed to the NBS annual newsletter and the "Wisconsin Health Care Professionals' Guide to Newborn Screening."

3. Outreach/Public Education—Enabling Services—Pregnant women, mothers, and infants

The Wisconsin EHDI/American Academy of Pediatrics (AAP) Chapter Champion submitted a grant proposal to the AAP. The proposal was funded and was used to work collaboratively with the Wisconsin Chapter of Hands and Voices to launch an awareness campaign during May, Better Speech and Hearing Month. Legislative invites were hand delivered by children and their parents, radio interviews were conducted and aired, and a breakfast with legislators was convened.

4. The Wisconsin Pediatric Audiology Training—Infrastructure Building Services—CSHCN

WSB presented at the WSHA fall update and annual spring conference on pediatric audiology topics and the Guide-By-Your-Side Program.

5. Home Births Initiative—Direct Health Care Service—Pregnant women, mothers, and infants

A grant was submitted to AHEC for a piece of hearing screening equipment for the Western Region home birth population.

6. Guide-By-Your-Side Program—Infrastructure Building Services—CSHCN

Regional interviews were conducted, and parent guides were hired.

7. WE-TRAC—Infrastructure Building Services—CSHCN

Based on analysis of data from the blood card, we are enhancing both automated and manual de-duplication processes in WE-TRAC. This is a necessary priority for system development. The pilot phased out beginning in May, and the new version began phased rollout statewide following completion of this development. We are also defining PCP involvement in WE-TRAC and the early intervention components of WE-TRAC, which include the State Birth to 3 and GBYS programs. The Comprehensive Hearing Loss (CHL) form, "Just-In-Time" information for physicians, and NBS data reports were also made available on the WE-TRAC website.

c) 2005 Plan/Application

1. Outreach/Public Education—Enabling Services—Pregnant women, mothers, and infants

WSB will continue to make available outreach materials related to the importance of screening such as "A Sound Beginning for Your Baby" to hospitals and providers through necessary reprinting. WSB will also provide consultation to the development of a Spanish version of the Babies and Hearing Loss Interactive Notebook for Families. WSB will distribute a mailing to pediatric PCPs regarding next steps in the care of a child with diagnosed as deaf or hard of hearing, as well as special considerations for conditions such as unilateral hearing loss and Usher's Syndrome.

2. Support Services for Parents—Enabling Services—CSHCN

The Third Annual Conference for families with deaf, deaf-blind, and hard of hearing children will be organized to occur in the winter/spring of 2005. The Guide-By-Your-Side Program will continue to be supported through ongoing training and promotion.

3. Birth to 3 Technical Assistance Network—Infrastructure Building Services—CSHCN

The Birth to 3 Technical Assistance Network will continue to become stronger through the systematic connections being built into the WESPDHH-Outreach project and will continue throughout 2004. The network will continue to provide critical technical assistance to local Birth to 3 programs. The network of consultants will receive ongoing training, technical assistance and support in 2005 and will be connected to the Parent Guides through one cooperative training effort. Discussions will continue with key partners to provide the Birth to 3 Technical Assistance Network with oversight and direction as well as to continue to foster support and commitment to the importance of the existence and function of this network.

4. WSB/Congenital Disorders Program—Population-Based Services—Pregnant women, mothers, and infants

WSB will continue to provide regular updates regarding hearing screening through the WSLH Newborn Screening Program Newsletter.

5. UNHS Implementation Workgroup—Infrastructure Building Services—CSHCN

The Workgroup will continue to meet quarterly. From this network of committed individuals new projects will be identified and addressed. This group will continue to advise the direction and focus of the Wisconsin Sound Beginnings Program.

6. WE-TRAC—Infrastructure Building Services—CSHCN

Phased statewide rollout will continue to hospitals, audiologist, and clinical practice organizations.

Development of the early intervention module will be completed, and the system will be rolled out to early intervention users. Development will include completion of the report functionality, and other changes based on user feedback.